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The experience of adjusting to a diagnosis of non-epileptic attack disorder (NEAD) and the subsequent process of psychological therapy

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ABSTRACT

Purpose: Research suggests psychological therapy as the treatment of choice for individuals diagnosed with NEAD. This study explored the experience of adjusting to a diagnosis of NEAD and engagement with therapy through a qualitative methodology.
Method: Semi-structured interviews were conducted with 6 people with a diagnosis of NEAD and analysed using thematic analysis.
Results: Six master-themes were generated, with four discussed. Two themes were not discussed due to previous coverage in the literature and their less direct relevance to the service context. Theme 1: 'understanding NEAD' incorporated participants' evolving understanding of the diagnosis and their reflections on this. Theme 2: 'I can't deal with you' centres on participants' accounts of relationships with professionals in the context of NEAD. Theme 3: 'experiences of psychological therapy' reflected participants' experience of being referred to psychology and gaining a deeper understanding of themselves through therapy. Theme 4: 'adjusting to life with NEAD' explores participants' views on living with NEAD and their expectations for the future.
Conclusion: This study extended previous research by highlighting the impact of how the diagnosis is received and understood on engagement in therapy. Improving awareness of NEAD amongst healthcare professionals is of key importance in reducing stigma and encouraging engagement in therapy.

1. Introduction

Non-epileptic seizures (NES) appear similar to epileptic seizures, but have no associated ictal electrical activity.[1] Approximately one in every five new patients within epilepsy services are reported to be experiencing NES and are diagnosed with non-epileptic attack disorder (NEAD).[2] NES are often misinterpreted as epileptic presentations,[3] although observable characteristics such as gradual onset and prompt cessation may help in their differentiation.[4] This lack of diagnostic clarity can have ramifications for patients' physical health[5] and understanding of NEAD, which in turn may reduce motivation to engage in appropriate therapeutic approaches.

Despite the growing knowledge base concerning physical ictal symptoms of NEAD, there is minimal research into subjective psychological experiences. When such research has taken place, it has tended to focus on the experience of receiving a diagnosis of NEAD. Patients often have restricted understanding of the link between NES and psychological factors, with feelings at the time of diagnosis including anger, confusion, and relief.[6] A specific strategy for communicating a diagnosis of NEAD has been proposed,[7] which aims to address all aspects of patients' illness representations. It has been reported that patients who are able to integrate their understanding of NEAD into their personal narrative appear more likely to accept the diagnosis.[8] Patients who accept and acknowledge the psychosocial nature of NEAD tend to report feeling more hopeful that change can occur, in comparison to patients who believed that their NES were organic in nature.[9]

Understanding NEAD as psychological in nature facilitates patient engagement in psychological approaches.[10] A range of psychological approaches have been advocated, including cognitive-behavioural therapy (CBT),[11] eye-movement desensitisation therapy (EMDR),[12] individual or group psychoeducation,[13] and brief psychodynamic interpersonal therapy.[14] Although there is no clear evidence base for adopting a particular psychological approach when working with NEAD,[15] over 80% of clinicians in a recent survey identified psychotherapy as particularly effective for NES.[16]

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Despite this assertion, there is a dearth of research which explores patients' perceptions of psychological therapy for NEAD. Although patients may have clear ideas about their hopes for therapy, there is often a sense of uncertainty as to whether therapy will be able to address their identified needs.[9] They hope that therapy will be a place in which they can seek answers, gain emotional release, and take control of their seizures. However, their ambivalence as to whether this would be provided by therapy may partly explain the high proportion of patients with NEAD who do not attend a first appointment of psychological therapy, or discontinue early in the process.[17]

Quantitative studies suggest that a range of approaches may improve coping strategies for people living with NES, for example group psychoeducation,[13] group interpersonal therapy,[18] and CBT.[19] Patient experiences of psychological therapy are mixed, however. Whilst some saw psychological input as a good opportunity to discuss problems, learn management techniques and develop acceptance of the diagnosis, others perceived it to be "opening up a can of worms" (p. 291)[6]. However, engaging in detailed reflection on the possible emotional aetiology of NEAD was seen by some patients as a beneficial aspect of psychological intervention, although this understanding was not always seen to be sufficient.[20]

This study aims to explore individuals' experiences of engaging in psychological therapy, and the process of adjusting to the diagnosis of NEAD. It will consider potential barriers and facilitators of engagement in therapy, from the participants' perspective. It will also explore whether people with NEAD perceive benefit from psychological input and how this may relate to the process of adjustment.

2. Method

Participants were eligible for inclusion if they had received a diagnosis of NEAD and attended at least one outpatient session with a psychologist[a] within an adult neuropsychology NHS service in North-West England. Patients who were deemed by their therapist as likely to become significantly distressed during an interview were not approached; nor were patients with other major neurological diagnoses. Ethical approval was granted by a local National Health Service (NHS) Research Ethics Committee and an NHS Trust Research Directorate. Potential participants were sent an information sheet, covering letter from their therapist, and an opt-in form. Participants were made aware that their decision would not be known by their therapist, and would not affect their care. Semi-structured interviews were undertaken, which lasted between 50 and 80 min.

2.1. Sample

The service received thirty referrals for patients with a sole diagnosis of NEAD in the 12-month timeframe, all of which came from general neurology clinics. Nineteen potential participants were contacted, seven expressed interest in the research, and six were interviewed (see Table 1). Of the six interviewed, three neurologists had initiated their referrals to the neuropsychology service.

2.2. Analytic strategy

A descriptive phenomenological approach to data collection and analysis was adopted, allowing exploration of the rich and complex experiences.[21] An inductive analytic approach was adopted, with codes and themes identified directly from the data.[22] The analysis was consistent with the five stages advocated by Braun and Clarke,[21] although the process was a recursive one during which the researcher moved between stages as required.

[a] This ensured that participants were able to comment on the experience of engaging in therapy.

3. Analysis

Six master themes were generated; three of these contained sub-themes (see Table 2). Verbatim extracts are provided via the numbers in parenthesis, which relate to Tables 3–6 (available online). Of the master themes, four are presented. The remaining themes, 'support and burden' and 'people just think I'm a nutter' are not discussed as they are less pertinent to the research question. These two themes related to how participants experienced living with NEAD, specifically the perceived burden placed upon their family, the acknowledgement of family support, and the perception that society regarded them as having mental health difficulties. Although it is likely that these experiences will have impacted upon participants' decision to engage in psychological therapy, it was outside of the bounds of this paper to consider these in detail.

3.1. Understanding NEAD

Participants discussed the process of gaining a diagnosis of NEAD and the introspective questions this provoked. The lengthy journey to gaining a diagnosis resulted in frustration and feeling rejected, whilst an implicit reliance on medical models increased ambiguity. Although participants appreciated the social acceptability of having a diagnosis, it did not necessarily provide meaning.

It's a long winded business. . .you get brushed off. The delay in receiving a diagnosis was seen as detrimental, and was often attributed to a lack of understanding by wider medical systems (3.1, 3.2), and the disbelief of staff (3.3, 3.4). Many participants believed that they were seen to be faking epilepsy (3.5), and were not taken seriously (3.6). This was also pertinent for partners, who worried that they were suspected of abuse (3.7). Participants believed that the diagnosing neurologist viewed NEAD as unimportant (3.9, 3.10) or doubted their symptoms (3.11). Physical investigations were viewed as inevitable by many participants (3.12), but caused Jim frustration, perhaps due to his psychological understanding of his seizures (3.13,3.14). However, the cessation of physical investigations was frustrating for participants who held a biomedical understanding, and left them feeling rejected (3.15). Nevertheless, participants did not highlight the wait between diagnosis and therapy as particularly long or difficult, suggesting that the close working relationship between neurology and psychology services effectively managed this potentially distressing period.

Sometimes you think what the hell have I got? Participants struggled to retain information presented to them about NEAD by the neurologist or psychologist (3.16, 3.17). For some, learning that their seizures may be psychological felt more distressing than discovering an organic cause (3.18). In addition, several participants voiced uncertainties about the diagnosis NEAD (3.19, 3.20, 3.21) and the potential for organic pathology (3.22). Despite this, almost all participants mentioned contributing psychological factors such as experiences of abuse (3.23), stress (3.24) and suppressing emotions (3.25). Participants struggled to apply psychological explanations to all seizures, particularly those which occurred at times of relative calm (3.26, 3.27). Contradictions were evident in participants' narratives, within which they referenced both psychological and organic understandings (3.28, 3.29), and used medically-oriented language when discussing psychological factors (3.30, 3.31).

Table 1
Demographic features of participants.

Pseudonym	Gender	Age (years)	Approximate time since NES onset (years)	Approximate time since diagnosis (years)	Number of sessions with psychologist
Emily	F	52	3	2	7
Jim	M	55	2	1.5	11
Lisa and Ben[a]	F	40	6	5	11
Olivia and Neil[a]	F	55	44	2	5
Jo	F	53	8	4	4
Hanna and Dominik[a]	F	29	20	2	9

[a]Indicates partner was present and contributed during interview.

We've got a label but no way of taking it off. Diverse views on the utility of the diagnosis were evident, both between participants and within their own thinking (3.32, 3.33). For many, the application of a diagnostic label granted legitimacy to their experiences, and provided a way to explain their symptoms to others (3.34). The diagnosis was used as retaliation against the scepticism encountered within participants' interactions with professionals and the public (3.35, 3.36), and reduced the self-doubt which had been fostered by experiences of being disbelieved (3.37, 3.38).

Jim experienced the diagnosis of NEAD as one of empowerment and positivity, due to the shift in perceived agency which accompanied the change in diagnosis from epilepsy (3.39). However, receiving the changed diagnosis was a shock and elicited strong emotions. Hanna and Dominic believed that receiving a diagnosis of NEAD suggested an expectation that she could automatically stop the seizures (3.40). The fact that this did not fit with their experience of the seizures as uncontrollable meant that the diagnosis felt invalidating and inaccurate.

Many participants struggled to understand explanations of the diagnosis (3.41) and were unsure of what the label of NEAD represented (3.42). The diagnosis did not always feel relevant to their experience (3.43), contributing to a lack of meaningfulness (3.44).

3.2. "I can't deal with you" – relationships with professionals

Participants discussed difficult relationships with professionals, often employing combative language and portraying this period as an active struggle with medical professionals (4.1, 4.2). This is unsurprising if participants' biomedical illness model were incongruent with professionals' hypotheses of psychological factors. No participants revealed an explicit psychological understanding of their seizures prior to receiving a diagnosis and the suggestion of such was often felt to imply fraudulency (4.3, 4.4). Some participants believed that doctors were unwilling to compromise or appreciate subjective knowledge (4.5). In addition, most participants perceived their health professionals as uncertain of how to work with them (4.6, 4.7). This is likely to have influenced participants' perception of NEAD as an ambiguous diagnosis, generating feelings of intense frustration (4.8). Despite this frustration, a number of participants recognised the inherent difficulties for professionals (4.9, 4.10). Some believed that generating a collaborative understanding of the confusing and complex nature could have made professional uncertainty more tolerable (4.11).

For some, the most difficult aspect of their relationship with professionals was their sense of being disbelieved, particularly by GPs (4.12, 4.13). Such experiences are likely to discourage individuals from reflecting on potential psychological explanations and influence their ability to engage in psychological therapy, from which Hanna was discharged because she firmly believed that her seizures were epileptic in nature (4.14).

In contrast to these difficulties, most participants also experienced positive interactions with professionals, which were highly valued. Some participants experienced a sense of relief when the professional shared their psychological understanding with them (4.15, 4.16). This positive experience was sustained through participants' interactions with staff at the neuropsychology service, with several participants commenting on their positive ethos (4.17).

3.3. Experience of psychological therapy

Participants discussed their initial reactions to being referred to a psychologist and subsequent experiences of engaging in therapy.

You're a bit odd…go and see this person. Several participants viewed a referral to psychology as indicative of mental health difficulties and worried about the consequences of attending (5.1, 5.2). This was exacerbated by a lack of information provided at the point of referral and the connotations attached to the title of psychologist (5.3). Family members often encouraged them to attend and accompanied them to an initial appointment (5.4).

Table 2
Master and sub-themes.

Master themes	Sub-themes
Understanding NEAD	It's a long-winded business…you get brushed off
	Sometimes you think what the hell have I got?
	We've got a label but no way of taking it off
I can't deal with you – relationships with professionals	
Experience of psychological therapy	You're a bit odd…go and see this person
	Going deeper
Adjusting to life with NEAD	My world has shrunk…but I've got my control
	Take me as I am or not at all
	Is this my life forever?
Support and burden	
People just think I'm a nutter	

Note: Themes not discussed in full are shown in italics.

Table 3
Selected quotes for the theme 'understanding NEAD'.

Subtheme	Quotation
It's a long-winded business… you get brushed off	(3.1) "The ambulance crew have turned around and said she's only having a fit…just leave her" (Lisa)
	(3.2) "It took so long and so many A&E admissions" (Ben)
	(3.3) "They can't get inside your head so it's not a big problem to them" (Emily)
	(3.4) "I just wanted to get it fixed and having doctors saying it's all in your head just doesn't help at all" (Jo)
	(3.5) "I'm being treated as someone who fakes epilepsy" (Hanna)
	(3.6) "They said she was play acting, as medical professionals you shouldn't even be suggesting that" (Ben)
	(3.7) "Because the seizures are so unknown, if that person is thrashing they bruise themselves a lot, there were several times when I was looked at as though I'd been abusing you" (Ben)
	(3.9) "This young man's been poncing about for two years you know, what's the crack?" (Jim)
	(3.10) "It took about three years to diagnosis, before we got a neurologist to look at you seriously" (Ben)
	(3.11) "I felt like I was actually making it up, you know, it was suggested that I was making it up [by the neurologist] (Hanna)
	(3.12) "All she knows is that she has a follow-up in one year…she feels rejected (Dominik)
	(3.13) "I got the impression he swept it under the carpet…I just sat down one day and said look, we don't seem to be getting very far here" (Jim)
	(3.14) "They have to do so many investigations before they get to it…it's a long-winded business" (Ben)
	(3.15) "That was very traumatic…when I was going through that phase the attacks were worse you know, so that's what makes me think it might be psychological" (Jim)
Sometimes you think what the hell have I got?	(3.16) "Is it just a title that they give you if they can't figure out whatever else it is…I can't remember what they told me about it, only that it was similar to epilepsy but it wasn't" (Jo)
	(3.17) "I don't remember much [of the explanation]" (Emily)
	(3.18) "The scan says I'm fine, but I'd sooner have something wrong" (Liv)
	(3.19) "Even though we've been given a title for the disorder…we still don't quite believe the title" (Ben)
	(3.20) "Sometimes you think what the hell have I got?" (Olivia)
	(3.21) "Is that what they are, my vacant things?" (Emily)
	(3.22) "We've been told the brain's complex, how do we know there's not another condition out there that needs opening up?" (Ben)
	(3.23) "Did my brain start shutting off when that guy first sexually abused me…my mind still seems to be locked as that lonely child" (Olivia)
	(3.24) "I think stress has got a huge part to play, especially for me" (Jo)
	(3.25) "Something you won't share, you keep it in your head for too long and then bang, it just hits" (Lisa)
	(3.26) "[The psychologist] thinks I get anxious. And then, I don't know, maybe I just cut off and it's like a safety valve. I do agree on some of them but when I was outside and I fell I was just pottering around" (Emily)
	(3.27) "It's hard to come to terms with the idea that it's something psychological…when it happens out of the blue. It would be understandable if we had an argument before or she was nervous or agitated, but everything was fine, we were OK" (Dominik)
	(3.28) "It's an accumulation of things, I think it goes back to your childhood" (Neil)
	(3.29) "I wonder whether you've got an electric impulse, a bleed up here" (Neil)
	(3.30) "Get to the bottom of what's causing it psychologically" (Jim)
	(3.31) "If you could open my brain to the bit where everything locks and find out…I would love to know" (Olivia)
We've got a label but no way of taking it off	(3.32) "It was good and bad…..I got a label, that I found great. Then the bit where [they] say…we can't change it. (Olivia)
	(3.33) "We've got a label for it but the trouble is we haven't found a way yet of taking it off" (Ben)
	(3.34) "Now we've got a label on it you can turn around and say that's what it is" (Neil)
	(3.35) "You can look people in the face and say this is NEAD" (Lisa)
	(3.36) "Now we've got a label you can turn around and say that's what it is" (Olivia)
	(3.37) "Before, I didn't know what it was, I used to think I was going round the twist" (Lisa)
	(3.38) "I wasn't making it up, it wasn't all in my head" (Jo)
	(3.39) "Something to work for now, something to word towards" (Jim)
	(3.40) "It's like somebody has told you, just think it's OK and stop having fits" (Dominic)
	(3.41) "I didn't really understand" (Jo)
	(3.42) "We don't know 100% what it is it's just there…I've got a condition called NEAD, that's all I can say" (Olivia)
	(3.42) "It was obvious to her that it was actually epilepsy" (Dominik)
	(3.44) "The title doesn't actually mean anything…it's just an answer for the condition" (Ben)

Due to the protracted diagnostic process, participants worried whether psychology would be any more helpful than avenues previously explored (5.5). Furthermore, a referral to psychology in the midst of further neurological investigations left participants feeling confused as to whether their seizures were organic or psychological in origin (5.6). A lack of understanding about the role of psychology could influence what participants expected of the service, for example an expectation of undertaking further medical tests (5.7).

A referral to psychology could also indicate that somebody was interested in helping (5.8), despite an ambivalence about whether it would be helpful (5.9) Some participants perceived therapy as a legitimate stage in the diagnosis (5.10), reducing the sense of stigma they experienced. For example, Jo's attitudes towards seeking help appear to have been positively influenced by health professionals in her family (5.11).

Going deeper. One participant described therapy as similar to a drug in its simultaneously powerful but hazardous nature (5.12). This metaphor seems pertinent to the uncomfortable, but ultimately rewarding, experiences of other participants, many of whom mentioned the difficult discussions experienced in therapy (5.13, 5.14). In Olivia's case, this seemed to "open a can of worms". However, the process resulted in other participants relating differently to their seizures, particularly around accepting their presence in their life and learning new ways to manage them (5.15, 5.16). Participants spoke about the trusting relationship that

Table 4
Selected quotes for the theme 'relationships with professionals'.

Theme	Quotation
"I can't deal with you" – relationships with professionals	(4.1) "I was. . .fed up of fighting" (Jo)
	(4.2) "I was angry. Cause you shouldn't say things like that, especially because I've been suffering with this and trying to cope with this for so many years" (Hanna)
	(4.3) "Everybody is trying to convince me that I am faking an epileptic seizure" (Hanna)
	(4.4) "Cause you're not physically ill, they don't think you're ill" (Emily)
	(4.5) "They have their theory and they stick to it. . .so that's how it all ends, that was the diagnosis and that's how it has to be" (Dominik)
	(4.6) "The neurologist was so vague, he didn't really know what he was on about" (Lisa)
	(4.7) "I can't deal with you" (Olivia)
	(4.8) "Oh there's nothing worse than having to see different people and they'll think it's something else and send you off in that direction and then when you go back you see somebody else who'll think oh no, you should have gone that way" (Emily)
	(4.9) "I shouldn't really have a do at [them] I suppose 'cause he's probably just as confused as I am" (Jim)
	(4.10) "Not being able to understand it myself, I suppose I don't blame them" (Jo)
	(4.11) "If I'd have had, not exposure but more regular updates from the [neurologist] (Jim)
	(4.12) "[GP] laughing straight into my face saying I have no epilepsy" (Hanna)
	(4.13) "[GP thought] what do you want now?" (Jo)
	(4.14) "I was still thinking that. . .the fits are at least partly caused by epilepsy and I couldn't forget about this idea. So they felt that because I still thought that I wasn't suitable for therapy" (Hanna)
	(4.15) "He told me about the condition and I just couldn't believe somebody actually believed me. . .I cried, all my frustrations had come out 'cause I was being believed and not being made a fool" (Lisa)
	(4.16) "The psychologist believed me basically, if they've given it a title they believe it's happening, I'm not making it up" (Jo)
	(4.17) "There everybody's so nice. . .it makes you feel like a person and not just a hospital number" (Emily)

Table 5
Selected quotes for the theme 'experiences of psychological therapy'.

Subtheme	Quotation
You're a bit odd. . .go and see this person	(5.1) "I was really forced into it. . .I thought there was a stigma on it. . .I was going round the twist and I was going to tend up in a psychiatric hospital" (Lisa)
	(5.2) "I thought I was mental and had to see [the psychologist]. I thought they would put me in a padded cell" (Emily)
	(5.3) "Just explain things–it's like you're a bit different and odd, go and see this person, they're an expert. And [the psychologist] is lovely but you just see what they are and immediately you just think oh, I'm mental (Emily)
	(5.4) "My son made me go in the end" (Emily)
	(5.5) "Are we going to go down the same road I've been down umpteen times, or are we going to get somewhere?" (Olivia)
	(5.6) "It's hard to take the treatment off the [psychologist] when the [neurologist] is faffing about" (Jim)
	(5.7) "I just thought maybe they might find something that didn't show up years ago that's like festered and might show up" (Olivia)
	(5.8) "I was happy because I took it as progress, I felt that somebody wanted to help to do something with this" (Hanna)
	(5.9) "It felt like somebody wanted to take an interest but are we really going to be any better off?" (Olivia)
	(5.10) "Just the next stage of diagnosis" (Jim)
	(5.11) "I've no qualms with psychologists; they just. . .make you see things in a different way. Like I said I've been brought up in a medical background so none of it has been any issue to me" (Jo)
Going deeper	(5.12) "One day it has to end. . .you know if you're on a tablet for a long time and. . .if you just stop it's like woah but if you gradually break it off you can lose that contact. . .I just don't w ant it to be sudden" (Emily)
	(5.13) "I didn't want to [talk about the past] but then I thought well maybe I had to. . .but my mind, whatever bit locks it all in didn't really want to unlock it" (Olivia)
	(5.14) "When you go in it's, with talking about the past and things obviously which have gone wrong and have caused this. . .I always end up crying" (Emily)
	(5.15) "Since I've been seeing [the psychologist] my mind has altered. . .I think well I've got the condition, it's not going to take over my life I've just got to deal with it" (Lisa)
	(5.16) "Told me what it was and how to deal with it" (Jo)
	(5.17) "I'd have thought what a load of rubbish, but because you trust them and think they're obviously not doing it for fun, I'll give it a try" (Emily)
	(5.18) "I feel comfortable with them and if they advise me to do something I'll do it. With some doctors I feel like saying no" (Lisa)
	(5.19) "They gave me some relaxation tapes and I've found that those are very good" (Lisa)
	(5.20) "They've been very good, given me some grounding exercises and relaxation" (Jim)
	(5.21) "Told me about relaxation and gave me some tapes to listen to and you know, it was good but it didn't stop the problem really" (Hana)
	(5.22) "I said I know for a fact it's not good, I think I listened to about 20 s of it, you're joking with me aren't you?" (Olivia)
	(5.23) "It opened up other avenues. . .I've suppressed a lot of early life . . .it feels better, I feel more content. After every session I feel uplifted and confident and the more I go the more the attacks seem to be tailing off" (Jim)
	(5.24) "Through talking to them, they don't make me feel like I'm odd, like I'm a freak or something" (Emily)
	(5.25) "When you go to see some doctors you're only a number, whereas they have patience, they spend time" (Lisa)
	(5.26) "If you just stop it it's like woah, but if you gradually break off it eventually you can lose that contact but I, I just don't w ant it to be sudden" (Emily)
	(5.27) "I said that I don't feel the need to see them again, they've told me what it is, told me how to handle it and I didn't want to waste their time. . .they'd told me what it were and that was that" (Jo)

Table 6
Selected Quotes for the theme 'adjusting to life with NEAD'.

Subtheme	Quotation
My world has just shrunk...but I've got my control	(6.1) "I can't work because I endanger people" (Olivia)
	(6.2) "The radical lifestyle change that came with the attacks...I'm still getting my head around" (Jim) (6.3) "I'm happy in my little bubble. I don't get hurt" (Emily) (6.4) "I hate shopping...I can't wait to get out before somebody starts" (Lisa) (6.5) "I don't even see my siblings to be honest and they live on the same street, but I don't feel like seeing anybody" (Hanna) (6.6) "Whether I was dealing with it correctly or not, they were easing off...I've made sure my life isn't out of control at all. I rarely go out" (Jo) (6.7). "If I knew before that would be better, but I only know after when I've had one" (Emily) (6.8) "With these attacks I get nothing" (Olivia) (6.9) "I'd been feeling funny all day...my head was all fuzzy and funny" (Olivia) (6.10) "I'm staying indoors at home for weeks" (Hanna) (6.11) "When it comes to the controlling the fits and the change over the years, the psychologist's done that" (Lisa)
Take me as I am or not at all	(6.12) "Before, when I first started having them I was embarrassed...now it's just part of my life and if people don't like it they don't like it...they just have to take me with a pinch of salt" (Lisa) (6.13) "just want to get [the seizures] fixed" (Jo) (6.14) "instead of fighting it I allowed it to happen and it became part of my life" (Jo) (6.15) "I just want it to stop. I just want it to give over now" (Emily) (6.16) "If I go out now I'm frightened of having another one in the street" (Olivia)
Is this my life forever?	(6.17) "It lulls you into a false sense of security and you think, I haven't had one for three or four weeks, this is amazing! And all of a sudden something happens and you're back to square one" (Jim) (6.18) "I got up to work in a charity shop for a day, well half a day, and I've started cleaning the church for half a day...so life is good at the moment" (Jo) (6.19) "With the route I'm going I'm in a safe environment...it's just finding an employed that will take me on...there's no reason why they shouldn't. I'll be leading a full life back again (Jim) (6.17) (6.20) "They'll go away hopefully one day but until then I can't do nothing about it" (Lisa) (6.21) "I just give up" (Olivia) (6.22) "This is my life forever" (Jo)

needed to be formed between client and therapist prior to these difficult discussions being held. This sense of trust also allowed participants to try out techniques which they may have dismissed as futile, if introduced by somebody whom they did not trust (5.17, 5.18).

Learning practical techniques for seizure management was beneficial (5.19, 5.20), and one participant utilised some of the coping skills she had developed through therapy during the interview. However, these techniques did not always feel relevant to the seizures, even if they felt helpful in other areas of life (5.21). This felt particularly pertinent for participants who were looking for a way to completely stop the seizures, rather than a way in which to manage their intensity or regularity. Moreover, for participants who did not believe that such exercises would help, it was very difficult to even try this approach (5.22).

Alongside such techniques, some participants found that their seizures began to reduce as they gained a psychological understanding of them. Therapy provided a space within which unresolved conflicts from the past could be discussed, and the process of this had wide-reaching effects, including the reduction of seizures (5.23). Participants also alluded to the normalisation experienced through therapy (5.24) and the perception that the psychologist was willing to spend time to understand their experiences (5.25). It appears that this aspect of therapy is noticed and valued by individuals with NEAD and may be of particular importance considering the previous experiences of invalidation reported by participants.

The ending of therapy could provoke extreme anxiety for some participants. Extending the drug metaphor, Emily talked about her wish to "taper off" contact with the psychologist, and her fear of it being ended suddenly (5.26). This seemed to be particularly pertinent due to past experiences of services terminating their care abruptly. However, Jo took the ending into her own hands and finished therapy after only two sessions. This was based on her belief that she had been given an explanation for her seizures during the first session and practical advice on managing these, and she could not gain anything further from the process (5.27).

3.4. Adjusting to life with NEAD

Several aspects of adjusting to NEAD, both before and after receiving a diagnosis, were discussed by participants. These included struggles to regain a sense of control over lives and bodies, the integration of NEAD into self-perceptions and visions of the future.

My world has just shrunk...but I've got my control. All participants talked about the restrictions they had placed on their lives to cope with the unpredictability of seizures (6.1). Adjusting to these changes was an on-going process which no participants felt they had yet achieved (6.2). Some participants spoke about their home as the only place of true safety (6.3) and conceptualised others as hazardous, therefore avoiding public places (6.4). For some, the seizures reduced their motivation for seeing friends and family (6.5) and their social world became very constrained. Participants recognised that, whilst these restrictions were not necessarily helpful, they did assist in controlling seizures (6.6).

Perceptions of control were central to all participants, many of whom wished for a tangible warning before seizures (6.7). However, participants who spoke about wanting warnings were able to identify particular at other points of the interview (6.8, 6.9). Thus, lack of awareness of the association between warning signs and seizures made it impossible to gain a sense of control. Participants who were unable to predict their seizures faced more restrictions on their life than those who felt they could predict and manage their seizures more effectively (6.10). Some participants felt that accessing psychological therapy had assisted them in

gaining more control over the seizures, although this control still felt variable (6.11).

Take me as I am or not at all. For a small number of participants, seizures were no longer a shameful or embarrassing affliction, but an integrated and valid aspect of their self (6.12). For Lisa, this sense of "take me as I am or not at all" was developed through a supportive therapeutic relationship and normalisation experienced by attending the neuro-rehabilitation unit. Jim likened his experience of having seizures to a physical disability, and felt as though this was an aspect of him that others, including potential employers, would have to accept. The expectation of others accepting the seizures suggests that Jim himself accepted these as part of his subjective sense of self.

However, the process of developing acceptance was not linear and participants may have fluctuated in the degree to which they perceived their seizures to be an ordinary part of life. For example, Jo sometimes spoke about her seizures as being an affliction which needed to be fixed, whilst at other times reflected that she had accepted them as part of her life (6.13, 6.14).

Many participants, however, viewed their seizures as something very separate to their conceptualisation of themselves. This led to a sense of being in conflict with the seizures, battling against them to make them stop (6.15). This lack of integration of their seizures into their sense of self contributed to participants' fears of leaving the house and being amongst other people, who were perceived to be equally unaccepting of the seizures. Such perceptions of seizures as extraordinary and unusual were accompanied by feelings of isolation, powerlessness and loss (6.16).

Is this my life forever? All participants mentioned their hopes, fears and beliefs about the future. For some a dichotomy of being either completely seizure free or completely unwell existed (6.17). Participants viewed themselves as making progress if they did not experience a seizure for a period of time, but the experience of then having a seizure generated feelings of hopelessness and frustration.

Almost all of the participants did not work, in part due to their seizures. However, the only two participants who spoke about the impact of this were Jim and Jo, who both saw returning to work as a marker of their progress. For Jo, life felt good because she had recently been able to begin working again, despite continuing to experience seizures (6.18). Although Jim had not returned to work at the time of the interview, he had constructed a positive image of the future and had taken steps towards this, including beginning to retrain in a career which offered a safer environment for him to manage his seizures (6.19). Thus, although both Jo and Jim expected that they would continue to manage seizures, they were able to make positive adaptations that they believed would help them to live a valued life.

However, for many other participants, there was a sense of passivity about the future, with people feeling powerless to change their experiences. For some, there was a sense of hope that their seizures would stop in the future, but without an accompanying sense of agency within this process (6.20). For others, their seizures were seen as likely to continue into perpetuity, and a sense of hopelessness ensued (6.21, 6.22).

4. Discussion

Fig. 1 represents the analysis in diagrammatic form. Participants discussed their understanding of NEAD, the influence of receiving a diagnosis after a lengthy process, the experience of

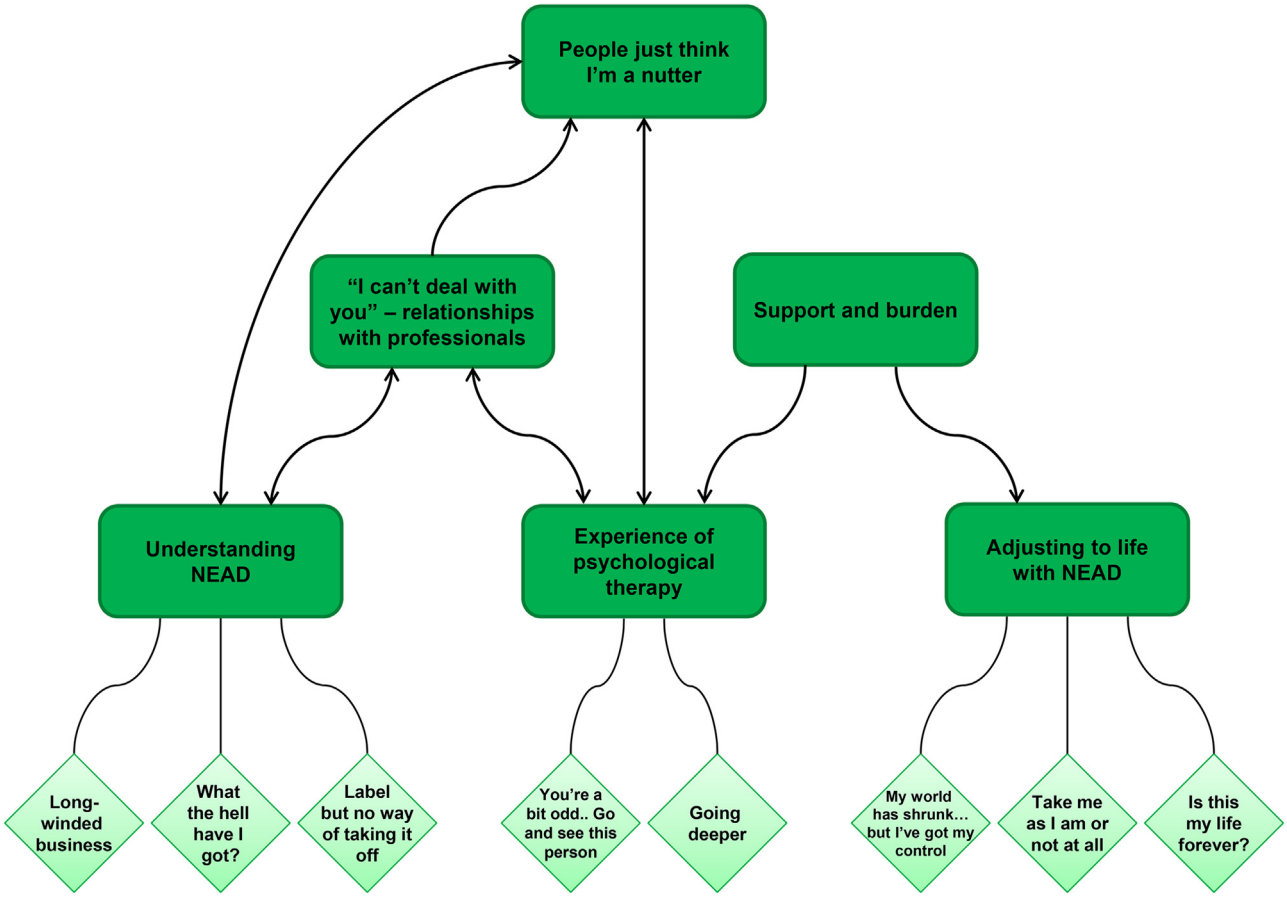

Fig. 1. Diagrammatic representation of master- and sub-themes.

psychological therapy as powerful but difficult, and the ongoing sense of uncertainty.

There was a sense of uncertainty in the diagnosis of NEAD, which was exacerbated by participants' perceptions of professional uncertainty. This was reflected in parallel considerations of psychological and physical explanations for symptoms, perhaps reflecting an implicit reliance on epilepsy as an illness prototype, despite acceptance of psychological explanations.[10]

Difficult interpersonal experiences with professionals is consistent with the use of conflict metaphors in wider MUS literature.[23] Many participants felt as though they were disbelieved by professionals, which may have resulted in attempts to convince them of the reality of distress and ill-health. This is incompatible with the recovery process,[24] and may have made it difficult for participants to accept a referral for psychological therapy. This sense of being disbelieved may have stemmed from the incongruity between the participants' and professionals' understanding of their seizures. May et al.[25] suggested that "when medical and lay models of symptoms are congruent, doctors' evaluations of the patient are less problematic" (p. 152); it is likely therefore that patients' evaluations of doctors will also be affected by *incongruence* in working models. Difficult experiences with professionals hindered the development of a psychological understanding of seizures and impeded meaningful engagement with therapy. However, difficult professional interactions sometimes led to a perception of the psychologist as genuinely interested, therefore facilitating engagement.

Receiving the news that they did not have an organic pathology and would be referred to psychology could feel like a rejection to participants. Considering the likelihood that individuals experiencing NEAD may have faced difficult and abusive relationships,[26] it is possible that their relational schemas are highly attuned to the potential for abandonment and rejection. Thus, it is important to ensure that an onwards referral is explained in a sensitive and open manner with clients. Although referral to psychology was sometimes perceived to indicate mental health difficulties, this notion dissipated with time. These assumptions reflect the predominance of negative stereotypes around seeking psychological help in Western culture, and can result in stigma, reduced self-esteem and poor engagement.[27,28]

Participants developed a psychological understanding of their seizures, although this was not always explicitly acknowledged. Therapy was seen as a space in which participants gained a deeper understanding of their selves in the context of NEAD and developed a different relationship with their seizures. However, for some this felt like "opening a can of worms", a sentiment which echoes previous research.[6] This is consistent with research suggesting that disclosing difficult information to therapists can provoke feelings of shame and anxiety, but that "the consequences of these disclosures, although reflecting an amalgam of emotional experiences, are primarily perceived by clients as positive".[29] (p.345) For participants who were able to identify warning signs, therapy enabled them to gain a sense of control over their seizures.

Most participants, however, found it difficult to imagine life without NEAD. They conceptualised themselves as under the control of their seizures, rather than in control of them. This sense of powerlessness has been conceptualised as an existential construct, determined by the situation of living with chronic illness.[30] and illustrates a "chaos narrative", in which no endpoint can be envisioned.[31] Frank[31] cautions healthcare professionals not to rush people to relinquish this narrative, as this threatens to dismiss the chaos caused by the illness as "the patient's personal malfunction" (p. 110).

5. Limitations

The findings of this study must be considered with the context of any methodological limitations. The sample size of six participants is relatively small, and although this allowed for an in-depth understanding of the data from each participant, it may have resulted in a biased sample. NEAD is a heterogeneous experience,[32] making it unlikely that our small sample captures the vast range of experiences. Further research with a wider range of people diagnosed with NEAD would be beneficial in determining the degree to which the current findings apply to this heterogeneous population.

This study did not recruit individuals who declined an invitation for psychological therapy, or were deemed by their therapist as likely to be distressed by the interview. These groups of patients excluded from recruitment may have had different experiences of services than those who could talk about their experiences more easily. Furthermore, it is possible that the themes identified were influenced by the specific diagnostic experiences of participants, who all received their diagnosis from one of three neurologists.

6. Conclusions and implications for practice

This study provides an in-depth exploration of individuals' adjustment to living with a diagnosis of NEAD and the experience of being invited to and engaging in psychological therapy. Vigilance to signs of rejection or dismissal by healthcare professionals can jeopardise their engagement with psychological services. Adjustment to a diagnosis of NEAD is assisted by engagement in therapy, which supports individuals to gain a new perspective on their seizures and reduces the self-stigma they may have experienced at diagnosis. However, whether or not the individual engages in therapy may be affected by their previous experiences of healthcare professionals, their understanding of the diagnosis, and family support.

Raising awareness of NEAD and the complexities of working with people with MUS should be prioritised, particularly for front-line staff. Integration of the psychology team at the first point of diagnosis would provide an opportunity to discuss therapy before attending and hence reduce apprehension.

Conflict of interest statement

The authors report no conflict of interests.

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